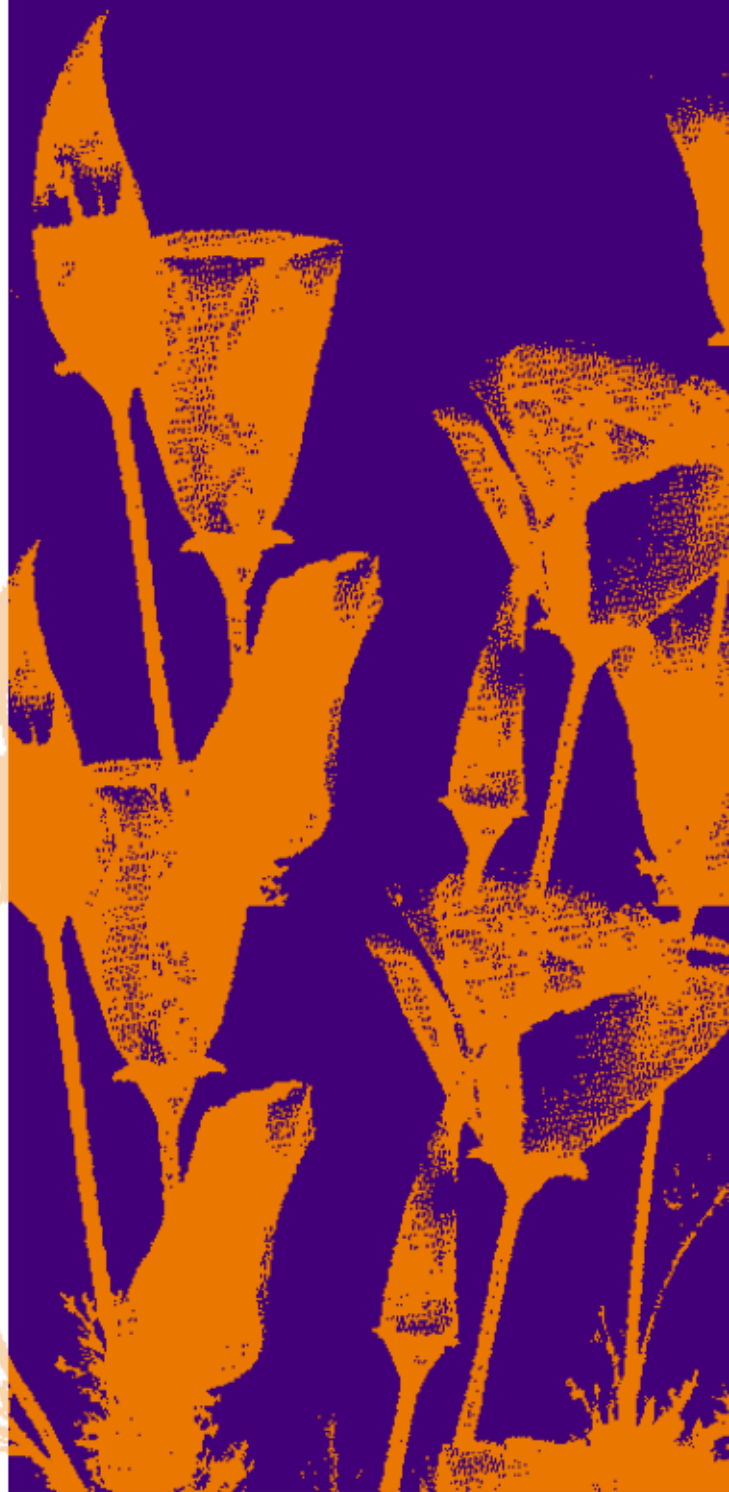


From Vision

To Action

***A Strategic
Plan
for
Preventing
Disabilities
in California
1997 – 2001***

*Prepared by the Disability Prevention
Advisory Group*



From Vision To Action

*...to guide efforts in preventing disabilities and
lessening their impact on the lives of people in
California...*



ALBERT L. ANDERSON, D.D.S.
1923-1997

The Disability Prevention Advisory Committee dedicates this plan to the memory of “Dr. Al” Anderson, in recognition of his lifelong commitment to serving others and improving quality of life for persons with disabilities. A man of extraordinary talent, compassion, good humor, and integrity, Dr. Anderson served children and adults in his dental practice for more than forty years. He advocated and provided services for children and adults emphasizing prevention through appropriate dental care.

Dr. Anderson’s contributions were many. He served as President of the American Society of Dentistry for Children, the American Academy of Pedodontics, and the Pan American Council of Dentistry. He was Director of the National Foundation of Dentistry for the Handicapped; Vice-Chair of the President’s Committee on Mental Retardation; a member and Vice-Chair of the California State Council on Developmental Disabilities; and Chairman of the California Medical Assistance Commission.

Dr. Anderson was committed to his family and community, giving his time and heart to everything he started. Through his leadership and vision in the area of clinical practice and public policy, Dr. Anderson leaves an enduring legacy for individuals with disabilities and all Californians.



Dear Colleague:

The societal costs of disabilities can be staggering in terms of human suffering, premature death, costly utilization of resources, reduced productivity, and quality of life. Fortunately, it is possible to prevent many serious disabilities and associated secondary conditions without contributing to the stigmatization of disabled people.

We already have many successes to celebrate: the enactment of California's motorcycle and bicycle helmet laws; primary enforcement of seat belts; lowering of legal blood alcohol concentration (BAC) levels in drivers; and, the implementation of highly successful prevention and early childhood intervention programs (e.g., Early Start). But our job is far from over. Many challenging issues cut across all levels of prevention including alcohol misuse, the integration of people with disabilities into managed care, and insufficient access to data and information. Given the magnitude and many causes of disabilities, and the large and complex constellation of programs and services in California, it is critical to initiate and implement a coordinated statewide disability prevention effort.

From Vision to Action is the result of a collaborative planning process around disability prevention never before undertaken in California. The Disability Prevention Advisory Committee (DPAC) developed recommendations to be implemented over the next five years which address primary, secondary, and tertiary levels of prevention and specific areas of injury-related disabilities (traumatic nervous system injuries), developmental disabilities (alcohol-related birth defects, cerebral palsy, and spina bifida), and secondary conditions. The plan provides common direction and guidance, and can be used as a tool to raise awareness about disability prevention issues, facilitate the formation of policy, stimulate action, and provide information for resource allocation. The goals and recommendations contained within are not listed in priority order, and many recommendations identify what needs to be done, not necessarily how to do it, leaving the door open for creative strategies and solutions.

The successful implementation of plan recommendations will require new and sustained partnerships and a shared commitment to preventing disabilities in California. The field of disability prevention is emerging and evolving as more and more people relate what they are doing with the prevention of disabling conditions, disabilities, and secondary conditions. No matter which end of the prevention continuum you work, whether your focus is on promoting bike helmets or preventing bed sores, we all have in common the goals of enhancing quality of life through prevention.

On behalf of DPAC, I invite you to review this strategic plan, use it to educate and advocate for disability prevention in your organization and among your constituencies, and work together with DPAC member organizations to prevent disabilities in California.



Robert A. Jacobs, M.D., M.P.H., Chair
Disability Prevention Advisory Committee

The comments and recommendations expressed in this plan are those of the Disability Prevention Advisory Committee (DPAC) and do not necessarily reflect the activities or plans of the California Department of Health Services.

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I. THE MAGNITUDE OF DISABILITY

Disability is a serious public health, social, and economic issue. Disabilities affect individuals, families, and communities in terms of human suffering, costly utilization of health and human services resources, reduced or lost productivity, and premature death. Disabilities can result in substantial reductions in quality of life and are associated with increased dependence on health care and social service systems. Growing attention to the broad range of issues related to disabilities resulted in the passage of landmark antidiscrimination legislation, the Americans with Disabilities Act of 1990, and the development of a national agenda for the prevention of disabilities.

The successes of modern medicine in saving the lives of many people born with physical or mental impairments or who have life-threatening diseases and injuries are adding to the number of people with disabilities. Medical advances also mean that people are living longer and experiencing disabilities as they age. Accurate figures on the number of people with disabilities are difficult to obtain and vary widely depending on how disability is defined. According to one estimate, during 1991-1992 almost 48.9 million Americans (19.4% of the U.S. population) had a disability.¹ These include people with disabilities resulting from chronic diseases, birth defects, or injuries. In the 1990 Census, which gathered information on health conditions only on civilian and noninstitutionalized persons aged 16 and older, 1.5 million people (6.8%) in California reported having a mobility or self-care limitation. Disabilities seem to be more common in certain ethnic groups, the elderly, the poor, and those with less education.

“According to one estimate, during 1991-1992 almost 48.9 million Americans (19.4% of the U.S. population) had a disability.”

No matter how disabilities are defined or counted, it is clear that they have a large economic impact on both the public and private sectors. The cost of 101 federal programs specifically targeted to and funded for people with disabilities, plus the portion of Medicaid and Medicare which benefits people with disabilities, exceeds \$175 billion a year.² One study that attempted to define the economic costs of disability in the United States estimated that all economic losses, taking into account medical care costs and reduced productivity, approach \$200 billion a year.³ In California alone, nearly 600,000 children are being served in special education programs at an annual cost in excess of \$2.5 billion.

Injury-Related Disabilities

Injury has finally begun to receive long overdue recognition and attention as a major public health problem. Each year in the U.S., injuries kill about 150,000, permanently disable 80,000, and cost more than \$100 billion in lost productivity and medical care.^{4, 5} The toll of injury-related deaths would be much higher were it not for primary prevention efforts, improvements in prehospital transport and trauma care, and the development of organized trauma systems. However, medical advances contribute to an increasing number of people surviving injuries that used to be fatal. Many of these people are left with lifelong impairments.

Of all injury-related disabilities, those associated with traumatic nervous system injuries (TNSI) are the most costly. Traumatic injuries of the brain and spinal cord often cause significant physical, neurophysical, and psychosocial deficits that require extensive long-term treatment and rehabilitation. The emotional and social effects can be devastating to the individual, the family, and society in general. In California, there may be as many as 35,000 persons with spinal cord injury (SCI), with about 1,000 new injuries occurring each year.⁶ The most common major physical impairments for SCI are muscle paralysis and loss of sensation. Estimated lifetime costs for medical treatment and rehabilitation of SCI can be as much as \$751,000 per person.⁷ In 1992, 20,123 people in California were hospitalized with Traumatic Brain Injury (TBI).⁸ Many survivors of TBI live with lifelong cognitive deficits, emotional or behavioral impairments, and physical disability. The lifetime costs to care for one person with severe TBI have been estimated at \$4.6 million by the National Brain Injury Association.

In general, African American and Hispanic males are at highest risk for TNSI in California. The leading causes include traffic-related mishaps (motor vehicle, motorcycle, bicycle, pedestrian), falls, and acts of violence.⁹ More than 25 percent of the nation's 10,000 to 15,000 spinal cord injuries each year are the result of violence.¹⁰ There is also a strong association between alcohol and TNSI. One study found that over half of all incidents leading to traumatic brain injury involve alcohol.¹¹ Alcohol-related traffic crashes are reported to be the leading cause of spinal cord injury for young Americans.¹²

Developmental Disabilities

Developmental disabilities begin during an individual's developmental years and usually persist throughout life. They are caused by conditions such as mental retardation, cerebral palsy, alcohol-related birth defects (fetal alcohol syndrome and fetal alcohol effects), structural birth defects (e.g., spina bifida), epilepsy, and others. These conditions, associated with low birth weight, premature birth, congenital anomalies, perinatal substance abuse, or hereditary disorders, can often be prevented. For example, fetal alcohol syndrome (FAS), caused by drinking during pregnancy and diagnosed in about 70 infants per year in California, is the most common identifiable cause of preventable mental retardation.¹³ Pregnant teens and women who do not receive early prenatal care are at greatest risk of having children with birth defects and developmental disabilities.

Developmental disabilities affect about four percent of the U.S. population under age 21.¹⁴ State and federal laws that govern service agencies differ in their definitions of developmental disabilities with respect to age of onset and eligible conditions. Currently, California does not have a data collection system designed to determine incidence or prevalence. However, one estimate puts the number of Californians who currently meet the federal definition of developmental disabilities at 574,308.¹⁵ Using the widely accepted national prevalence estimate of 1.8 percent, by the year 2000 California will be home to 630,000 people with developmental disabilities. As of December 1995, the Department of Developmental Services (DDS) was serving 133,310 persons who meet the more restrictive criteria dictated by California law through its regional center system and providing 16,598 infants and toddlers with prevention and early intervention services.¹⁶ At the same time, California special education programs were serving 34,059 pupils with developmental disabilities, of which 939 were ages 0-2.¹⁷

“By the year 2000, California will be home to 630,000 people with developmental disabilities.”

Federal, state, and local governments spend billions of dollars each year on programs and services for children with developmental disabilities. According to a study conducted by the California Birth Defects Monitoring Program in 1992, the estimated lifetime cost for one person with cerebral palsy is \$503,000.¹⁸ Costs include medical treatment, developmental services, special education, and lost productivity. The lifetime cost for one person with spina bifida, a birth defect which may be prevented through maternal consumption of folic acid, is \$294,000. For some individuals with cerebral palsy and spina bifida, costs may be many times higher than these estimates.

Secondary Conditions

People with disabilities are often at risk of developing secondary conditions (health problems that arise from, or are related to, the main cause of disability) that can result in declining health status, functional capacity, and quality of life. With few exceptions, such as extensive research on the prevention of pressure sores, secondary conditions have received little attention nationwide from researchers, health care professionals, and social service providers despite the fact that many are preventable. Epidemiologic information on the incidence, prevalence, and risk factors for secondary conditions is scarce. Lack of data limits the ability to accurately estimate the financial and human costs associated with many secondary conditions, although clinicians and advocates maintain they are high. In one known example, the average cumulative cost per pressure sore was estimated at \$58,000. Since about 35-40% of people with spinal cord injuries develop pressure sores of varying severity, the cost associated with this avoidable secondary condition is large.¹⁹

“With few exceptions, secondary conditions have received little attention nationwide despite the fact that many are preventable.”

Risk factors implicated in the development of secondary conditions include inadequate health care and poor personal hygiene, nutritional problems, smoking, and lack of physical activity. Alcohol abuse, discussed previously as a risk factor for primary disabilities, also contributes to secondary conditions by undermining the rehabilitation process. Persons with disabilities are at greater risk than the general public for alcohol abuse. Alcohol and other drug abuse rates for people with disabilities such as spinal cord and head injury exceed 50 percent.²⁰ Many people who abused alcohol before the onset of their disability continue abusing it after. Others start drinking after their disability has occurred as a way of attempting to deal with the changes in their lives. Early identification and treatment of people with disabilities who abuse alcohol and an increased focus on health promotion and disease prevention could dramatically decrease the incidence of secondary conditions in this special population.

Aging With a Disability

For persons with disabilities, the typical changes that everyone experiences as part of the aging process often pose serious health problems. Joints, muscles, and organ systems may begin to decline in function earlier and more abruptly than in non-disabled persons. More pain, decreased functioning, and the threatened loss of independence associated with aging and disability can lead to long-term stress and a greater likelihood of secondary conditions. Information is lacking on the natural history and distinct changes that occur over the lifespan of individuals with disabilities. Further research and education are needed so persons with disabilities and their service providers can better understand and address age-related biological, psychological, social, and economic issues.

II. CONCEPTS OF DISABILITY AND DISABILITY PREVENTION

Although understanding of the medical, behavioral, social, and economic aspects of disability is growing, confusion exists over terminology and disability concepts, even among professionals in disability-related fields. In 1991, the Institute of Medicine (IOM) Committee on a National Agenda for the Prevention of Disability prepared a report for CDC and the National Council on Disability. This report, *Disability in America*, clarifies disability concepts and proposes a simple framework for describing disability.²¹ The definitions and concepts that follow are taken directly from, or based upon, *Disability in America*.

Definitions

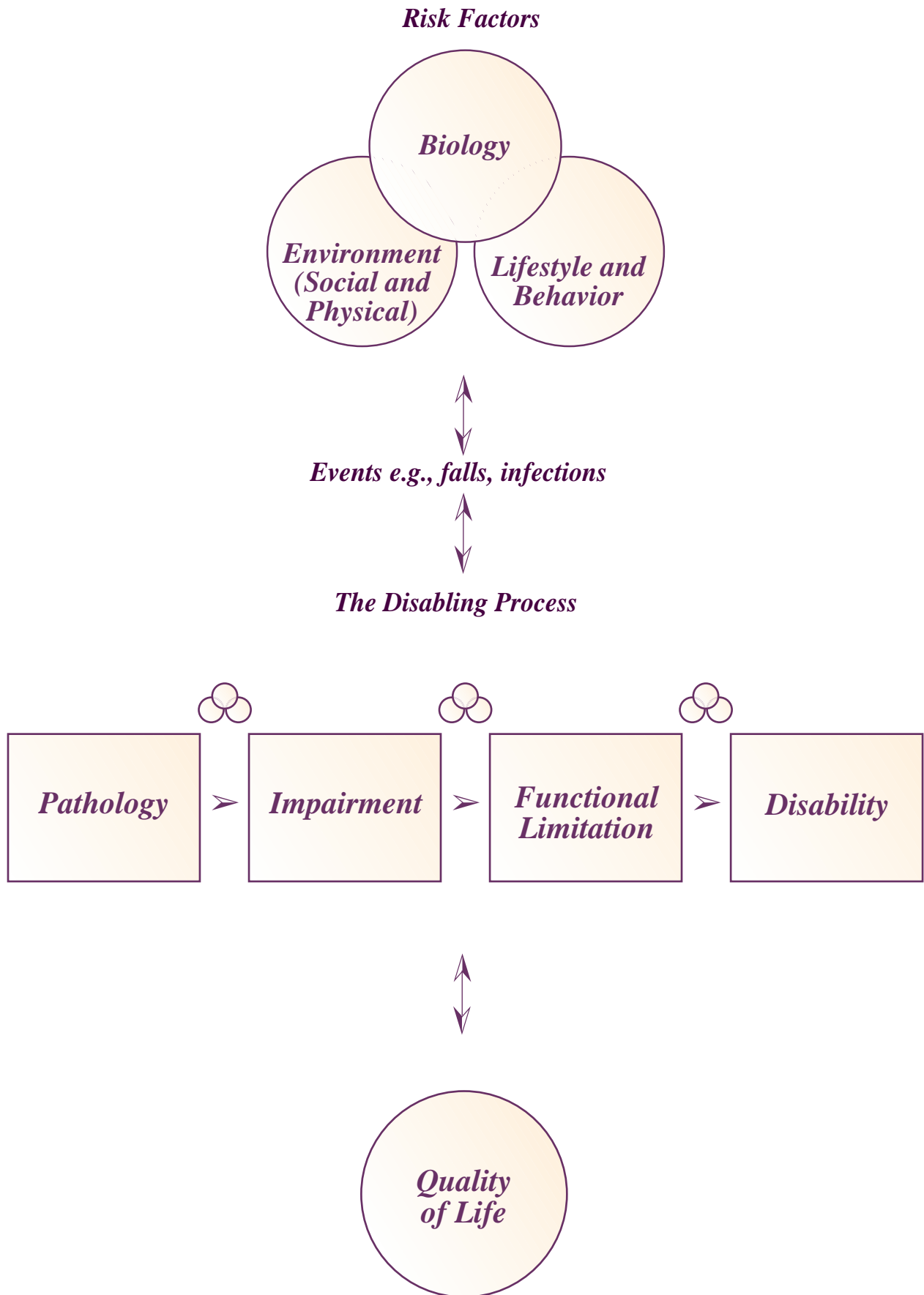
The term **disability** refers to limitations in physical or mental functions, caused by one or more disabling conditions, resulting in the inability to carry out socially defined tasks and roles that individuals generally are expected to be able to do. The term **disabling condition** refers to any physical or mental health condition, including pathology (active disease) as well as impairment (loss of mental, anatomical, or physiological structure or function), that can cause disability. Examples of disabling conditions include cerebral palsy, spina bifida, and paralysis resulting from a spinal cord injury. A **secondary condition** is any health condition that occurs as a direct result of having a disabling condition. Secondary conditions include pressure sores, contractures, muscle atrophy, obesity, cardiopulmonary disease, and depression. The phrases **disability prevention** and **prevention of disability** include the prevention of disabling conditions and their progression toward disability, the prevention or reduction of disability itself, and the prevention of secondary conditions.

Understanding Disability

Good disability prevention strategies must be built on sound basic knowledge of the relationships among risk factors, disabling conditions, quality of life, and secondary conditions. In developing a framework for a national disability prevention program, the IOM Committee sought to identify issues and needs that cut across the major categories of health conditions that can result in disability. They developed the following model to explain the disabling process and define disability prevention based on the work of Saad Nagi and the World Health Organization (WHO).



A Model for Disability



At the center of the model is the **disabling process**, which is composed of four related but distinct stages: pathology, impairment, functional limitation, and disability. Depending on the circumstances, one stage may or may not lead to the next. Disability prevention efforts can be directed at any of the three stages that precede disability and at the disability stage itself, where efforts can focus on reversal of disability, restoration of function, or prevention of secondary conditions associated with a disability.

Risk factors are biological, environmental (social and physical), and lifestyle or behavioral characteristics that affect health. Examples of risk factors for disabilities include alcohol use, lack of prenatal care, and poor access to public services. Identifying risk factors is a first step toward developing preventive interventions.

Quality of life refers to many aspects of personal well-being not directly related to health. Perceptions of personal independence and quality of life clearly influence how a person responds to challenges at each of the four stages of the disabling process and, therefore, influences overall health. Strategies that reduce the threat of diminished quality of life can be effective interventions for preventing disability.

As suggested in this model, disability involves a complex interactive process. Although disability always begins with pathology or impairment, it is not inevitable that people with these conditions become disabled. There are usually many points in the process at which to intervene and improve quality of life. How the health care system responds to a disease, injury, or condition in terms of medical care, assistive technology, and social support services will affect the extent of an individual's functional limitation and the potential for progression to disability and secondary conditions.

“Disability involves a complex interactive process. There are usually many points in the process at which to intervene and improve quality of life.”

Public Health and Disability Prevention

All successful public health strategies involve early identification of risk factors followed by measures to eliminate or reduce them. The public health model of disease prevention delineates three categories of prevention—primary, secondary, and tertiary. This same model is applicable to the prevention of disabilities.

Primary prevention seeks to reduce susceptibility, control exposure to disease or injury-causing agents, and eliminate or minimize behaviors and environmental factors that increase the risk of disease or injury. Interventions can include environmental modifications, health promotion and education to encourage healthy behaviors (e.g., programs emphasizing physical activity or alcohol prevention), and clinical preventive services (e.g., preconceptional and prenatal counseling).

Secondary prevention involves attempts to reduce damage, both physical and psychosocial, once exposure to disease or injury has occurred. Examples of approaches include the utilization of safety equipment (e.g., seat belts, bicycle helmets), early detection and treatment of disease through periodic screening of individuals at high-risk (e.g., screening for diabetes), the provision of high quality emergency medical services to people who sustain traumatic nervous system injuries, and early intervention services provided to children born with disabling conditions (e.g., those associated with perinatal exposure to alcohol).

Tertiary prevention concentrates on averting the progression of a disabling condition toward disability and on preventing or limiting secondary conditions, additional impairment, and functional limitations. Rehabilitation measures, including counseling, environmental adaptations, and mobility training aimed at restoring or maintaining function, are examples of tertiary prevention. So are promoting the utilization of appropriate assistive technology and continuity of care. Tertiary prevention efforts can also be directed at modifying or eliminating physical and social obstacles to personal autonomy and societal participation.

Given the dynamics of the disabling process and the variety of risk factors, primary, secondary, and tertiary preventive measures will often be required in concert in order to interrupt the disabling process and the progression toward disability. The application of public health principles to disability prevention, including surveillance, applied research in epidemiology, and the implementation of effective community interventions, can help decrease morbidity from disabling conditions and increase the number of persons with disabilities who live independent and productive lives.

III. A PLAN FOR ACTION

The Planning Process

In 1992, the California Department of Health Services (DHS) was awarded a four-year grant from the Disabilities Prevention Program at the Centers for Disease Control and Prevention (CDC) to build state and local capacity in disability prevention. The DHS **Office of Disability Prevention (ODP)** was established and charged with planning and coordinating information and activities, establishing systems of surveillance, providing training and technical assistance, and using epidemiological approaches to identify risks and target interventions to reduce disability in California.

The **Disability Prevention Advisory Committee (DPAC)** convened in May 1994 to provide guidance and counsel to the ODP in the development and implementation of this state plan. To ensure planning efforts were coordinated and broadly representative of diverse interests in the field of disability prevention, 21 members were appointed to DPAC, representing a cross-section of state and local government, private service agencies, consumer organizations, advisory councils, professional associations, and academia. Membership consists of consumer and caregiver advocates, people with disabilities, and individuals with expertise in epidemiology, public health, emergency services, acute care, rehabilitation, and education. See Appendix A for a list of DPAC members, consultants, and staff.

The Committee reviewed current information and worked on issues in three major areas: 1) developmental disabilities, caused by alcohol-related birth defects, cerebral palsy, and spina bifida; 2) injury-related disabilities, caused by traumatic nervous system injury; and, 3) secondary conditions associated with primary disabilities. Time and resources did not permit consideration of all disabilities, however many aspects of the plan apply to disabilities associated with mental retardation, chronic diseases, mental health, and others.

DPAC tried not to duplicate the efforts of other groups. Every attempt was made to integrate and compliment other plans, papers, and research. Major documents considered during the planning process included: *The Strategic Plan for Injury Prevention and Control in California 1993-97*; *Recommendations for Research on Spinal Cord Injury in California*; *the State Council on Developmental Disabilities State Plan 1995-97*; *Disability in America: Toward a National Agenda for Prevention*; *Preventing Secondary Disabilities Among People with Spinal Cord Injuries*; and, *Preventing Secondary Conditions Associated with Spina Bifida or Cerebral Palsy: Proceedings and Recommendations of a Symposium*. Also, to ensure the plan represented and responded to California's diverse disability prevention constituency, a draft was shared with representatives of many agencies, organizations, and interest groups.

“ 21 members were appointed to DPAC, representing a cross-section of state and local government, private service agencies, consumer organizations, advisory councils, professional associations, and academia. ”

Mission Statement

The purpose of the strategic plan is to guide efforts in preventing disabilities and lessening their impact on the lives of people in California.

This plan addresses the needs of people at risk for developing disabling conditions, and those with disabilities, to minimize the effects on quality of life. Primary prevention is clearly important, but emphasis is also placed on developing interventions that can prevent progression from pathology and impairment to disability and secondary conditions. This plan provides a framework for the development of state and local policy, and serves as a useful educational tool to increase awareness and understanding of disability prevention issues and mobilize statewide efforts to advance the field of disability prevention in California.

Goals and Recommendations

Many priority and cross-cutting issues in the field of disability prevention were identified in the strategic planning process and provided the basis for formulating recommendations to be carried out over the next five years. Estimates of time and resources needed to implement each recommendation are included. The goals and recommendations that follow are consistent with and supportive of CDC's national efforts and many Health Promotion and Disease Prevention Objectives for the Nation (see Appendix B). They are not presented in order of priority.

Goal A: SECURE ADMINISTRATIVE AND LEGISLATIVE SUPPORT FOR DISABILITY PREVENTION

Rationale: *Reducing disabilities in California requires a comprehensive and coordinated approach. New collaborative relationships between public and private agencies and organizations must be built and maintained. Disability prevention constituencies must become more involved in the legislative process to increase awareness among lawmakers and to further improvements in this area.*

A “lead” organizational unit within the Department of Health Services (DHS) that provides leadership, support, and a clear focus, is crucial to disability prevention in California. With responsibility for planning, coordination, and evaluation, such a unit can foster strong sustained participation and capacity at the state and local levels.

1 Year A1: DHS should make permanent the Office of Disability Prevention (ODP), so it can continue disability-related surveillance activities; develop, implement, and coordinate state and local interventions; provide professional training and education; and conduct public information activities based on this Strategic Plan.

Cost: Similar to that incurred by the disability prevention grant (CDC), approximately \$400,000 per year

5 Years A2: ODP will promote the inclusion of primary disability prevention and the prevention of secondary conditions into all major administrative initiatives, including the Year 2000 Objectives for the Nation, health care reform, welfare reform, women’s and children’s health, and multicultural health.

Cost: Could be accomplished with existing resources

5 Years A3: The Disability Prevention Advisory Committee (DPAC) should continue to facilitate interagency collaboration and monitor the implementation of the *State Plan for the Prevention of Disabilities in California*.

Cost: Would be included in cost for recommendation A1

5 Years A4: ODP will provide a mechanism for DPAC to follow pending state and federal legislation so members can provide expert consultation and monitor or influence legislation or actions related to disability prevention.

Cost: Could be accomplished with existing resources



Goal B: PROMOTE COOPERATIVE DEVELOPMENT AND IMPLEMENTATION OF DISABILITY PREVENTION PROGRAMS AND STRATEGIES

Rationale: *Many public and private sector programs are addressing the public health and social issues related to preventing disabilities, but do so independently of each other. Effective delivery of preventive programs to people at high risk of developing disabling conditions and to those who already have disabilities requires a shared commitment, coordination of effort, and multidisciplinary approach. Public and private sector providers must work together on common disability-related issues, sharing expertise and resources to develop, implement and evaluate successful primary, secondary, and tertiary prevention strategies and programs.*

5 Years B1: ODP, with input from DPAC, will disseminate information and promote cooperation among disability prevention programs by convening an annual conference or participating in related conferences or programs.

Cost: Could be accomplished with existing or combined resources but, depending on the scope of the effort, may require additional resources of up to \$50,000 per conference

2 Years B2: ODP and the California Department of Education should explore the development of new disability prevention and awareness educational approaches for inclusion in the health curriculum framework for primary and secondary education.

Cost: Could be accomplished with existing resources

3 Years B3: ODP should convene an Alcohol-Related Disabilities Prevention Task Force to identify common issues being addressed by many diverse constituency groups, propose and promote solutions, and provide input into major public policy groups (e.g., the Governor's Policy Council on Drug and Alcohol Abuse). The task force would include representatives from the fields of alcohol prevention and treatment, alcohol policy, disability prevention, injury prevention (e.g., family violence, traffic safety, drowning prevention), maternal and child health, law enforcement, chronic disease prevention, education, and others.

Cost: Could be initiated with existing resources, but would require augmentation for support of approximately \$10,000 per year

- 3 Years B4:** ODP and the Alcohol-Related Disabilities Prevention Task Force, working with the Department of Alcohol and Drug Programs, the Department of Rehabilitation, the Department of Education's Healthy Kids Program, and the Department of Developmental Services, should develop and implement innovative strategies to provide alcohol prevention and treatment services to people with disabilities through existing service systems, consumer advocacy organizations, and independent living centers.

Cost: Planning could be initiated with existing combined resources. Additional resources of an indeterminate amount would be required in order to implement and evaluate model programs

- 5 Years B5:** DHS, in conjunction with federal, state, and local agencies, should continue to support local programs aimed at preventing traumatic nervous system injuries associated with traffic-related mishaps (motor vehicle, motorcycle, bicycle, pedestrian), falls, and violence.

Cost: Indeterminate. Depends on the breadth and scope of local programs

- 2 Years B6:** ODP will work with the DHS Children's Medical Services and Maternal and Child Health Branches, the Department of Social Services Office of Child Abuse Prevention, the Department of Developmental Services, the Department of Education, and other child abuse and injury prevention professionals, to promote and expand educational strategies to prevent Shaken Baby Syndrome.

Cost: Could be accomplished with existing combined resources

- 2 Years B7:** ODP will work with the DHS Office of Family Planning and Primary Care and Family Health Division, the March of Dimes, and the Department of Developmental Services to disseminate and implement a protocol for preconceptional counseling focusing on folic acid consumption (to prevent spina bifida) for women of childbearing age.

Cost: Could be accomplished with existing combined resources

- 3 Years B8:** ODP, in conjunction with health, rehabilitation, and education professionals and representatives from the disability community, should develop, implement, and evaluate model health education and health promotion programs for persons of all ages with disabilities which include information on secondary conditions related to aging.

Cost: Could be accomplished by pilot projects within existing DHS programs, however, implementation and evaluation costs are indeterminate

- 5 Years B9:** ODP will collaborate with Assistive Technology Centers, the Department of Rehabilitation, the Department of Developmental Services, the Department of Education's Clearinghouse for Specialized Media and Technology, and others to distribute information on new assistive technologies as they become available in order to increase independence and prevent secondary conditions.

Cost: Could be accomplished with existing combined resources



Goal C: INCREASE PUBLIC AND PROFESSIONAL EDUCATION, AWARENESS, AND SENSITIVITY RELATED TO DISABILITIES.

Rationale: *The prevention of disabilities and secondary conditions requires a new and different mind-set among many professionals and the general public. Prejudicial attitudes and behaviors directed at people with disabilities hinder efforts to lead productive lives. Education is the best means to eliminate stereotypes and promote opportunity and inclusion.*

In addition, the capabilities of medical service providers and other caregivers to prevent the development of secondary conditions must be enhanced. Medical care for people with disabilities is often provided by general practitioners with little education on disabling conditions or the identification and treatment of secondary conditions. Practitioners who are more informed about the principles and practices of disability prevention would better serve people with disabilities and those who care for them.

2 Years C1: ODP and DPAC will collaborate with the State Council on Developmental Disabilities Media Task Force and the Department of Education to design and implement a statewide media campaign to promote public understanding and acceptance of people with disabilities.

Cost: Could be initiated with existing resources, but depending on the scope of the effort and availability of funds from the State Council, substantial additional resources may be required

2 Years C2: ODP and the Alcohol-Related Disabilities Prevention Task Force, in cooperation with the Department of Alcohol and Drug Programs and professional associations, will facilitate the development of a training package for voluntary use in health professional continuing education programs which addresses alcohol-related birth defects (e.g., Fetal Alcohol Syndrome), alcohol's relationships to intentional and unintentional injuries, the link between disability and increased risk for alcohol problems, the stigma associated with alcohol abuse, and screening and referral practices.

Cost: Could be initiated with existing resources, but depending on the scope of the project, may require additional resources

5 Years C3: DHS will collaborate with the Department of Aging, consumers, and professional associations to include information on the complex and specialized health care needs of persons with disabilities and the prevention of secondary conditions associated with aging in continuing education programs for health care providers.

Cost: Could be initiated with existing resources, but may require additional resources for curriculum development

- 2 Years C4:** The Emergency Medical Services Authority, with input from the Department of Rehabilitation, DHS, representatives from local Emergency Medical Services agencies, and consumers, should initiate training for emergency medical service responders to work more effectively with people with disabilities (including training on specialized medical procedures, sensitivity, communication, and the implementation of the Americans with Disabilities Act).

Cost: Indeterminate. Depends on the scope of the project.

- 3 Years C5:** ODP should work with the DHS Licensing and Certification Program, the Community Care Licensing Division of the Department of Social Services, and the Department of Developmental Services to develop programs for training of long-term and residential care providers in care and communication techniques for persons with disabilities.

Cost: At a minimum, would cost \$50,000 if contracted out to develop a model training program

- 2 Years C6:** ODP will work with the Department of Developmental Services, the Department of Rehabilitation, representatives from acute care and rehabilitation hospitals, regional centers, and other long-term care organizations to promote education for case managers and discharge planners on community-based living options so people with disabilities may live in the least restrictive and most age-appropriate environment.

Cost: Could be initiated with existing resources

- 5 Years C7:** ODP will work with the Department of Education and the Commission on Teacher Credentialing to implement training standards for Education and Clinical Rehabilitation Specialists and identify the knowledge and skills necessary for all teachers to serve students with disabilities in general education settings.

Cost: Could be accomplished with existing resources

“I am confident that through coordinated efforts such as this, we will achieve great progress to prevent disabling conditions that impact the lives of so many persons living in California.”

— James M. Kooler, Dr. P.H., Deputy Director, Department of Alcohol and Drug Programs

“The Commission appreciates being included in the Strategic plan. The Commission staff would be happy to work with you as you implement the recommendations in the future.”

— Sam W. Swofford, Ed.D., Executive Director, Commission on Teacher Credentialing

Goal D: FACILITATE ACCESS TO DISABILITY PREVENTION SERVICES

Rationale: *The financing and delivery of services in California is complex, compartmentalized, and poorly coordinated, making it extremely difficult for people with disabilities, their caregivers and providers to effectively access the array of services they require. Many people are underserved, and relatively little attention is paid to prevention. This means that many people suffer preventable conditions and complications.*

Health care service delivery in California is also in a state of flux. More than 600,000 of the 5 million people who receive health care coverage through California's Medicaid program (Medi-Cal) are now enrolled in managed care systems and this number will continue to increase. The major shift from fee-for-service payment to managed care with capitated reimbursement presents new challenges and opportunities.

California's rapidly changing demographic profile creates yet another enormous challenge for its system of preventive services. Although they seem to be disproportionately represented among those at highest risk for developing or having disabilities, individuals from some ethnic and cultural backgrounds are underserved by the disability prevention system. The need to target high-risk groups not in the mainstream with culturally and linguistically appropriate information and outreach activities is critical.

1 Year D1: ODP will explore the feasibility of constructing an electronic public access database identifying institutions and community-based programs that provide free or low cost health care services to children and adults, including information on location, types of services provided, and method of payment.

Cost: Could be accomplished with existing resources

5 Years D2: ODP and the DHS Medi-Cal Managed Care Division should convene a workgroup to develop and evaluate managed care service delivery models (e.g., specialized plans or subspecialty components of plans) which improve access to preventive health services for people with disabilities. The workgroup would include representatives from state and local government agencies, primary and tertiary care providers, consumer and caregiver advocacy groups, and other constituencies.

Cost: Could be initiated with existing resources, but would require annual support of approximately \$100,000 per year

3 Years D3: ODP and representatives of the DHS Office of Multicultural Health will participate in the California Consortium on Developmental Disabilities and Cultural Diversity (sponsored by the University Affiliated Program, University of Southern California) to help influence the development of a culturally responsive system of services for people with disabilities.

Cost: Could be accomplished with existing resources

- 3 Years D4:** ODP, with input from professional organizations and constituency groups, should develop and implement strategies to ensure that persons with traumatic brain injuries (TBI) and their family and professional caregivers a) receive information on potential long term complications upon hospital discharge, and b) are provided appropriate referrals for preventive and rehabilitative care and social support services.

Cost: Indeterminate. Would depend on the scope of the effort

- 2 Years D5:** ODP should convene a workgroup with representation from other DHS programs, the Department of Rehabilitation, the Emergency Medical Services Authority, other state agencies, and special education transportation programs to a) review non-emergency transportation practices, criteria and standards, and make recommendations for training non-emergency transportation providers on how to provide services to people with disabilities, and b) implement strategies to educate caregivers and people with disabilities about when and how to access and utilize emergency medical services (ambulance and emergency room) and non-emergency transportation services.

Cost: Indeterminate. Would depend on the scope of the effort

- 1 Year D6:** ODP will encourage the American Association of Neurological Surgeons to develop guidelines for the management of traumatic nervous system injuries, and assist in efforts to disseminate guidelines once published.

Cost: Could be accomplished with existing resources

- 1 Year D7:** ODP should facilitate the preparation of a document for use by policy-makers which describes the designated systems of care model for treatment of traumatic nervous system injuries and how this model could apply to California.

Cost: Would cost \$75,000 if contracted out for development of the document

“The strategic plan is a comprehensive, thoughtful and ambitious program. Neurosurgeons, who are often asked to manage disabilities resulting from congenital, developmental or traumatic neurological problems, can only applaud such an effort.”

— Sidney Tolchin, M.D., President, American Association of Neurological Surgeons

“I applaud your efforts in addressing this area of interest and wish you every success in the realization of the goals.”

— Stephen Mayberg, Ph.D., Director, Department of Mental Health

Goal E: INCREASE SURVEILLANCE OF DISABILITIES

Rationale: *Surveillance of disabling conditions is inadequate. Disability-related data are collected at the state and local levels by a number of agencies. But for the most part, data are used only within the agency that collects them and for very limited purposes.*

Improved and expanded surveillance could play an integral role in the prevention of disabilities by 1) accurately describing populations of people with disabilities, 2) identifying the causes of disabilities and secondary conditions, 3) guiding the development and funding of prevention strategies, and 4) evaluating the implementation of selected interventions.

2 Years E1: ODP will convene a Disability Data Resources Committee, with representation from the Departments of Health Services, Developmental Services, Rehabilitation, Mental Health, Alcohol and Drug Programs and Education, the Emergency Medical Services Authority, and the Office of Statewide Health Planning and Development to a) discuss the collection and analysis of disability data, b) evaluate existing disability data sources, and c) produce recommendations for data system development.

Cost: Could be accomplished with existing resources

5 Years E2: ODP will continue surveillance of traumatic brain injuries based on hospital discharge data.

Cost: Could be accomplished with existing resources

5 Years E3: ODP should develop a pilot traumatic nervous system injuries (TNSI) registry, utilizing data files from TNSI Model Systems Rehabilitation Hospitals to describe secondary conditions, identify prevention strategies, and support clinical research.

Cost: Would require additional resources of approximately \$100,000 per year

5 Years E4: ODP will encourage the Behavioral Risk Factor Surveillance System (BRFSS) and other data systems to include or improve data elements relevant to the prevention of disabilities.

Cost: Could be accomplished with existing resources

1 Year E5: ODP and the Department of Social Services' Office of Child Abuse Prevention, with input from Child Death Review Teams, the California Brain Injury Association, the American Academy of Pediatrics, and others, will produce a proposal for reporting Shaken Baby Syndrome to DHS.

Cost: Could be accomplished with existing combined resources

Goal F: PROMOTE DISABILITY PREVENTION RESEARCH

Rationale: *Little is known about causes and risk factors for disabilities and secondary conditions. Research can help identify these risk factors and determine how best to control them.*

5 Years F1: ODP, the Department of Developmental Services, and the Developmental Disabilities and Managed Care Workgroup should conduct research on existing data sets (e.g., the Client Development Evaluation Report) to a) describe prevalence, cost, and preventability of secondary conditions associated with selected disabling conditions (e.g., cerebral palsy and traumatic nervous system injuries), and b) evaluate intervention strategies and special demonstration projects.

Cost: Individual research projects could range from \$20,000 to \$100,000 per year

5 Years F2: DHS should work with the Department of Developmental Services and the Department of Aging to conduct research on basic growth, development, and aging issues for persons with disabilities.

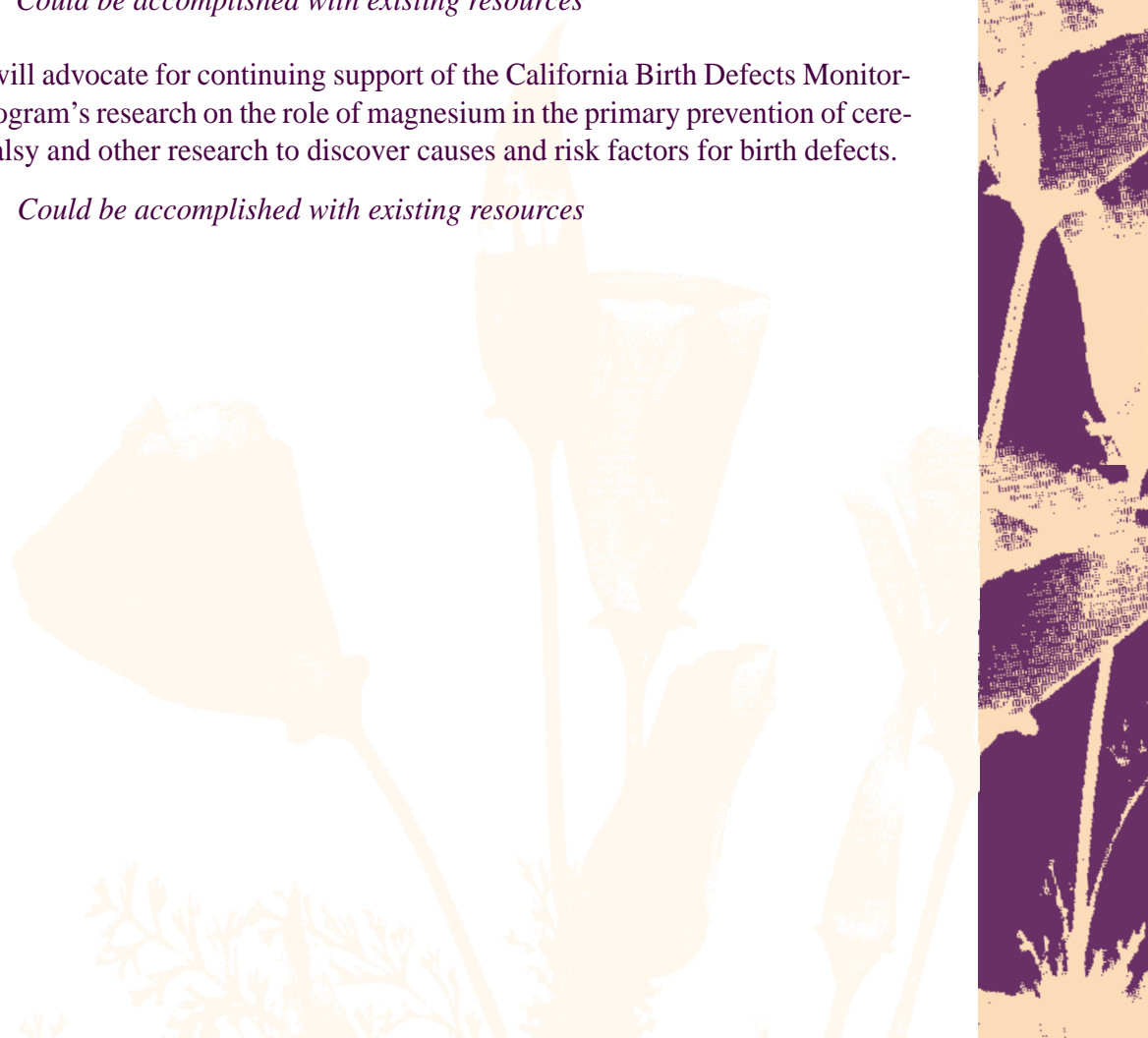
Cost: Individual research projects could range from \$20,000 to \$100,000 per year

2 Years F3: ODP and the DHS State and Local Injury Control Section will promote policies for testing and recording breath or blood alcohol concentrations (BAC) in injury patients at California hospitals to substantiate the role of alcohol in trauma.

Cost: Could be accomplished with existing resources

5 Years F4: DHS will advocate for continuing support of the California Birth Defects Monitoring Program's research on the role of magnesium in the primary prevention of cerebral palsy and other research to discover causes and risk factors for birth defects.

Cost: Could be accomplished with existing resources



Goal G: INCREASE AND STABILIZE FUNDING AND OTHER RESOURCES FOR DISABILITY PREVENTION

Rationale: *Responsibility for the prevention of disabilities in California rests with all levels of government and the private sector. California's public health system is overburdened with needs outstripping resources. Efforts to encourage linkages and resource sharing among public and private sector organizations are needed to support and expand disability prevention activities in California.*

5 Years G1: DHS will pursue continued and expanded financial support for disability prevention efforts from the Centers for Disease Control and Prevention (CDC), the Preventive Health and Human Services Block Grant, the Birth Defects Prevention Act of 1995 and other public and private funding sources.

Cost: Could be accomplished with existing resources

1 Year G2: ODP, in cooperation with the State Council on Developmental Disabilities, the Department of Education, and University Affiliated Programs, will a) convene a working group to identify and describe local, state, and national funding sources for disability prevention programs, and b) disseminate this information to public and private agencies and organizations seeking additional funding.

Cost: Could be accomplished with existing combined resources

1 Year G3: ODP, in cooperation with the State Council on Developmental Disabilities will determine how to introduce data elements into the U.S. Census and other data sources to determine a basis for funding and allocation of financial resources for disability prevention efforts.

Cost: Could be accomplished with existing resources

"The well-articulated goals of the plan are indicative of a significant amount of effort and research by many individuals. The AAPM & R supports your approach to preventing disabilities in California."

*— Ronald Henrichs, CAE, Executive Director
American Academy of Physical Medicine and Rehabilitation*

"Childrens Hospital Los Angeles, which treats nearly 200,000 children each year who are sick, injured, or have disabilities, applauds the efforts of the Disability Prevention Advisory Committee as it moves the model from reactive care to preventive care."

— Walter W. Noce, Jr., President and CEO, Childrens Hospital Los Angeles

NOTES





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APPENDIX A

Disability Prevention Advisory Committee (DPAC)

- ★ **Robert Jacobs, M.D., M.P.H., DPAC Chair**, USC University Affiliated Program Childrens Hospital Los Angeles/American Academy of Pediatrics/State Council on Developmental Disabilities
- ★ **Patricia O’Hare, DPAC Vice Chair**, Santa Clara Valley Medical Center
- **Joseph Barankin, Ph.D.**, Department of Education
- Felix Battistella, M.D.**, University of California, Davis, Medical Center
- Maridee Gregory, M.D.**, DHS Children’s Medical Services Branch
- Jeanne Heyerick, Ed.D.**, California Brain Injury Association
- ★ **Mary Lu Hickman, M.D.**, Department of Developmental Services
- Richard Hoffelt**, Shriners Hospitals for Children
- Edward Jasper**, California Spinal Cord Injury Task Force
- Kathleen Kelly**, Family Caregiver Alliance
- Jess Kraus, Ph.D., M.P.H.**, State Injury Control Advisory Task Force
- Kathleen Lankasky**, UCP of Alameda-Contra Costa Counties
- Nancy Lara-Moscardini**, Marin Center for Independent Living
- Robert Martinez**, Department of Aging
- ★ **Marita McElvain**, Department of Mental Health
- Marc Morin, M.D.**, California Medical Association
- Raymond Peterson, M.D., M.P.H.**, Association of Regional Center Agencies
- Jerry Reynolds**, United Cerebral Palsy Association of California, Inc.
- Darryl Sexton, M.D.**, California Conference of Local Health Officers
- Dan Smiley**, Emergency Medical Services Authority
- Robert Waters, M.D.**, Rancho Los Amigos Medical Center

- ★ Executive Subcommittee Members
- Editing Subcommittee Members

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- Ron Dieckmann, M.D., M.P.H., San Francisco General Hospital
- Janet Eaton, State Council on Developmental Disabilities
- ★ Priscilla Enriquez, March of Dimes Birth Defects Foundation, Bay Area Chapter
- Joyce Fung, Rancho Los Amigos Medical Center
- Robert Haining, M.D., Children's Hospital, Oakland
- Mary Beth Harrod, Head Trauma Support Project, Inc.
- Laura Hill, Department of Alcohol and Drug Programs, Office of Prevention
- Bruce Kennedy, Department of Social Services, Office of Child Abuse Prevention
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- Maureen McNeil, Emergency Medical Services Authority
- Lonnie Nolte, Residential Care Society
- Angel Nunez, Bay Area and Western Paralyzed Veterans of America
- ★ Susan Proctor, Emergency Medical Services Authority
- Bill VanGundy, VanGundy and Associates
- Denny Wight, California Department of Aging
- Howard "Pete" Wolfinger, M.D., Association of Regional Center Agencies

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- ★ Executive Subcommittee Members
- Editing Subcommittee Members

APPENDIX B

Related National Health Promotion and Disease Prevention Objectives

Physical Activity and Fitness

- 1.2** Reduce overweight to a prevalence of no more than 20 percent among people aged 20 and older and no more than 15 percent among adolescents aged 12 through 19.

Special Population Targets

<i>Overweight Prevalence</i>	<i>1976-80 Baseline</i>	<i>2000 Target</i>
1.2e People with disabilities	36%	25%

- 1.5** Reduce to no more than 15 percent the proportion of people aged 6 and older who engage in no leisure-time physical activity. (Baseline: 24 percent for people aged 18 and older in 1985).

Special Population Targets

<i>No Leisure-Time Physical Activity</i>	<i>1985 Baseline</i>	<i>2000 Target</i>
1.5b People with disabilities	35%	20%

Alcohol and Other Drugs

- 4.10** Increase the proportion of high school seniors who associate physical or psychological harm with heavy use of alcohol, occasional use of marijuana, and experimentation with cocaine, or regular use of cigarettes, as follows:

<i>Behavior</i>	<i>1989 Baseline</i>	<i>2000 Target</i>
Heavy use of alcohol	44%	70%

- 4.13** Provide to children in all school districts and private schools primary and secondary school educational programs on alcohol and other drugs, preferably as part of quality school health education. (Baseline: 63 percent provided some instruction, 39 percent provided counseling, and 23 percent referred students for clinical assessments in 1987).

- 4.19** Increase to at least 75 percent the proportion of primary care providers who screen for alcohol and other drug use problems and provide counseling and referral as needed. (Baseline data available in 1992).

Mental Health and Mental Disorders

- 6.5** Reduce to less than 35 percent the proportion of people aged 18 and older who experienced adverse health effects from stress within the past year. (Baseline: 42.6 percent in 1985).

Special Population Target

	<i>1985 Baseline</i>	<i>2000 Target</i>
6.5a People with disabilities	53.5%	40%

Violent and Abusive Behavior

- 7.4** Reverse to less than 25.2 per 1,000 children the rising incidence of maltreatment of children younger than age 18. (Baseline: 25.2 per 1,000 in 1986).

Type-Specific Targets

<i>Incidence of Types of Maltreatment (per 1,000)</i>	<i>1986 Baseline</i>	<i>2000 Target</i>
7.4a Physical abuse	5.7	<5.7

- 7.17** Extend coordinated, comprehensive violence prevention programs to at least 80 percent of local jurisdictions with populations over 100,000. (Baseline data available in 1993).

Appendix B (continued)

Unintentional Injuries

- 9.2 Reduce nonfatal unintentional injuries so that hospitalizations for this condition are no more than 754 per 100,000 people. (Baseline: 887 per 100,000 in 1988).
- 9.4 Reduce deaths from falls and fall-related injuries to no more than 2.3 per 100,000 people. (Age-adjusted baseline: 2.7 per 100,000 in 1987).
- 9.9 Reduce nonfatal head injuries so that hospitalizations for this condition are no more than 106 per 100,000 people. (Baseline: 125 per 100,000 in 1988).
- 9.10 Reduce nonfatal spinal cord injuries so that hospitalizations for this condition are no more than 5 per 100,000 people. (Baseline: 5.9 per 100,000 in 1988).

Special Population Target

<i>Nonfatal Spinal Cord Injuries (per 100,000)</i>	<i>1988 Baseline</i>	<i>2000 Target</i>
9.10a Males	8.9	7.1

- 9.11 Reduce the incidence of secondary conditions associated with injuries of the head and spinal cord to no more than 16 and 2.6 per 100,000 people, respectively. (Baseline: 20 per 100,000 for serious head injuries and 3.2 per 100,000 for spinal cord injuries in 1986).
- 9.12 Increase use of occupant protection systems, such as safety belts, inflatable safety restraints, and child safety seats, to at least 85 percent of motor vehicle occupants. (Baseline: 42 percent in 1988).
- 9.13 Increase use of helmets to at least 80 percent of motorcyclists and at least 50 percent of bicyclists. (Baseline: 60 percent of motorcyclists in 1988 and an estimated 8 percent of bicyclists in 1984).
- 9.18 Provide academic instruction on injury prevention and control, preferably as part of quality school health education, in at least 50 percent of public school systems (grades K through 12). (Baseline data available in 1991).
- 9.21 Increase to at least 50 percent the proportion of primary care providers who routinely provide age-appropriate counseling on safety precautions to prevent unintentional injury. (Baseline data available in 1992).
- 9.22 Extend to 50 states emergency medical services and trauma systems linking prehospital, hospital, and rehabilitation services in order to prevent trauma deaths and long-term disability. (Baseline: 2 states in 1987).

Maternal and Infant Health

- 14.4 Reduce the incidence of fetal alcohol syndrome to no more than 0.12 per 1,000 live births. (Baseline: 0.22 per 1,000 live births in 1987).
- 14.12 Increase to at least 60 percent the proportion of primary care providers who provide age-appropriate preconception care and counseling. (Baseline data available in 1992).

Diabetes and Chronic Disabling Conditions

- 17.2 Reduce to no more than 8 percent the proportion of people who experience a limitation in major activity due to chronic conditions. (Baseline: 9.4 percent in 1988).
- 17.14 Increase to at least 40 percent the proportion of people with chronic and disabling conditions who receive formal patient education including information about community and self-help resources as an integral part of the management of their condition. (Baseline data available in 1991).

Clinical Preventive Services

- 21.1 Increase years of healthy life to at least 65 years. (Baseline: An estimated 62 years in 1980).
- 21.2 Increase to at least 50 percent the proportion of people who have received, as a minimum within the appropriate interval, all of the screening and immunization services and at least one of the counseling services appropriate for their age and gender as recommended by the U.S. Preventive Services Task Force. (Baseline data available in 1991).

For more information, please contact:

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Emergency Preparedness and Injury Control Branch
Office of Disability Prevention
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Sacramento, CA 94234-7320
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<http://www.dhs.cahwnet.gov/prevsrv/cdic/epic>